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CANCER CAREGIVERS' DISCRIMINATION AND ITS IMPACT TO QUALITY OF LIFE

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Abstract

Family caregivers can face many challenges in their caregiving role like employment discrimination, making accomodations to work, low average monthly income etc. This is also the case for the cancer caregivers in the albanian context. The aim of this study is to explore the impact that caregiving has in cancer caregiver's Quality of Life, mediated by the socio – economic status. The participants of this study (*N*=377) were cancer caregivers for at least one month for an hour/per day. They were contacted at the University Hospital "Nene Tereza" in Tirana, at the Oncology Section. The research instrument consisted in socio – economic questions and the Flanagan Quality of Life Scale (1982). Results indicated that cancer caregivers had low family monthly income and were mostly unenmployed which correlated positively to Quality of Life.

Keywords: Caregivers discrimination, quality of life, employment, socio – economic status

Introduction

Family responsibilities discrimination, also called caregiver discrimination, is employment discrimination against workers based on their family caregiving responsibilities. Pregnant women, mothers and fathers of young children, and employees with aging parents or sick spouses or partners may encounter family responsibilities discrimination. They may be rejected for hire, passed over for promotion, demoted, harassed, or terminated — despite good performance — simply because their employers make personnel decisions based on stereotypical notions of how they will or should act given their family responsibilities("Family Responsibilities Discrimination", 2012). This leads to a lower family monthly income, which affects the caregivers quality of life (Williams, Devaux, Petrac & Feinberg,

2012). In some circumstances discrimination against caregivers may constitute unlawful disparate treatment (NSBA, 2014).

The financial impact on working caregivers who leave the labor force due to caregiving demands can be severe. A recent study suggests that family caregivers age 50 and older who leave the workforce to care for a parent or other sick members of their family lose, on average, nearly $304,000 in wages and benefits over their lifetime (MetLife Mature Market Institute, 2011)

According to the Caregiving in the U.S. 2009 survey, nearly seven in ten (68 percent) family caregivers of adults age 50 and older report making accommodations at work. Workers with eldercare responsibilities report the kinds of workplace effects that open up employees to discrimination, most commonly arriving late, leaving early, or taking time off during the day to provide care (64 percent), but also taking a leave of absence (17 percent) or reducing work hours from full to part time (9 percent). An estimated 10 percent of these family caregivers quit their jobs to give care or choose early retirement (National Alliance for Caregiving and AARP, 2009)

This can be the case for cancer caregivers in the albanian context as well as in other developing countries. Psychosocial studies for chronic illnesses in Albania have been sporadic. As a result of the demographic and epidemiologic transition there is a probability that the cardiovascular and tumoral diseases, diabetes and others to become more frequent, while in the industrialized countries these diseases are in decline for the last two decades. These are statistics that indicate a living reality, which means much more than the numbers presented in a table or graphic. Nowadays, early detection of cancer and progress made with existing therapies as well as the reveal of new ones, has resulted in a better prognosis for cancer patients. ("The stages of cancer", 2011).

Early diagnosis, advancements in cancer treatment, extension of the survivorship and tendency for outpatient treatment are associated with complex help given out of the hospital from the patient's caregivers. Literature and studies in the caregiving field had in focus family members of individuals with mental health problems, e.g. schizofrenia or dementia, while there is a tendency towards exploring the problems of the chronic patients caregivers, including here cancer patients (Schulz, O'Brien, Bookwala & Fleissner, 1995). The caregivers role can be challenging. Caregivers usually have many needs unmet, problems with physical and mental health and they can be indirectly discriminated because of their status. Being a caregiver can be a noble duty, but on the other hand it relates to problems with work, low socio – economic status and low levels of quality of life.

Definition of caregiving. Caregivers are individuals that help relatives or friends with limited abilities to conduct their everyday activities,

without being paid for this duty. Different words can be put on before the term "caregiver" like e.g. "family member", "spouse", "parent", "child", "young male/female" etc. to to refer to the different situations of offering care and to differentiate them from the payed caregivers. Around half of caregivers are excluded fron paid work because of the many demands and responsibilities that caregiving for a vulnerable individual has (Schofield et al., 1998).

An overall definition describes the caregivers as "the individuals, which are responsible for caring for another person, whom suffers from mental health problems, has different physical abilities or has a damaged health because of his disease or age" ("Being a caregiver", 2012)

Aim of the study. The aim of this study is to explore the effects of cancer caregiving role to the caregivers socio – economic status and its relation to quality of life.

Research questions. The research questions of this study are as follows:

1. What are the effects of being a caregiver to the socio – economic status of the caregivers?
2. Which is the relation between the socio – economic status of the cancer caregivers and their quality of life?

Literature review

Caregivers needs. Caregivers constitute a category of people who have specific unmet needs (Soothill *et al.,* 2001). In developed countries health professionals assist in identifying these needs and in planning interventions to address them. Some of these interventions are psychosocial support, vacation, information, referral and advocacy. However, caregivers themselves are not always clients of health institutions or social services. There are cases where these services are used by caregivers, but only to help the care recipient (Keefe, Guberman, Fancey, Barylak & Nahmaish, 2008).

Research in the field of care had in focus family members of individuals with mental health problems like schizophrenia or dementia (Baumgarten, 1989; Schulz, O'Brien, Bookwala & Fleissner, 1995). Early diagnosis, advances in treatment, length of survival and a trend for treatment outside the hospital has added responsibilities of carers, but has also extended the duration of care. Given the tendency of recent years to a shorter stay in hospital, patients must increasingly manage their own treatment, including here very strong and often side effects. consequently, the caregiver's load has increased and their role in patient support is even more important (Kissane & Bloch, 2002). Patient's caregivers are not only their family members. They may have the most diverse relationships, such as relatives, friends, neighbors or others (Hudson & Payne, 2008). Caregivers

are a valuable source of essential and unpaid support, serving as a complement to other health services, those formal (Haley, 2003 cited in Stenberg, Ruland & Miaskowski, 2010).

Quality of life to cancer caregivers. Quality of life can be assessed by the various instruments, qualitative or quantitative. For this reason, the findings of various studies may include quality of life as a whole or its various aspects (physical, psychological, social and spiritual) for caregivers. The overall quality of life is a perception that varies between studies. Husbands of women with gynecologic cancer and wives of men with testicular cancer were satisfied with their quality of life (Tuinman, Fleer, Hoekstra, Sleijfer & Hoekstra-Weebers, 2004). In longitudinal studies, higher average scores for caregivers who were on therapy were relatively stable in time, measured before and after therapy and, in some cases, after the death of patients (Gill, Kaur, Rummans, Novotny & Sloan, 2003). In all cases, the overall quality of life was low at the time that patients did radiotherapy, bone marrow transplant or were in palliative care. The caregivers quality of life worsened when the patients had brachytherapy or a palliative surgery (Borneman *et al.*, 2003).

Physical aspects such as fatigue, trouble sleeping, lack of appetite and need for recuperation were reported by women patients with prostate cancer (Kornblith, Herr, Ofman, Scher & Holland, 1994). Axelsson and Sjödén (1998) found that wives suffered from insomnia and needed help to take care for the hygiene and dressiung of the patients, needs which were growing over time.

Methods

This study was conducted in the Oncology Hospital, which is located in the University Hospital Center "Mother Teresa" in Tirana. Although oncologic services are not provided only by the hospital, the highest percentage of cancer patients are in this hospital.

Sample. This study is based in a convenient sample. An important issue for the selection of the sample for this study was that of defining the status of caregivers. Before taking part in the study, and filling the questionnaire participants should answer “yes” in the following question: “Are you the person that gives care most for this patient or is it someone else?” If the answer in this question was yes then the participants should meet the below inclusion criteria.

Inclusion criteria. Caregivers in this study should be at least 18 years old and they should have the main responsibility of offering direct care to a patient with cancer for at least one hour per day. They should also be unpaid caregivers, like family members, relatives or friends. Only one person for a patient could have the status of caregiver, so for one patient there were only

one caregiver – participant. Finally, the last criterion was the time of caregiving: it should be at least one month.

The sample size was calculated based on the confidence level (95%), and for a N = 20.000 because the real number of cancer caregivers is not known. So, the final sample size was n = 377 participants.

Quality of Life Scale (QoLS). Quality of Life Scale is comprised of 16 items, while the previous versions had 15 items (Flanagan, 1982). This instrument is categorized according to the sum of the answers, in order to conclude in a final result. Participants should be encouraged to fill all the answers. Non answered items can be replaced with the mean value for this item. Flanagan did not report internal consistency reliability (Cronbach's alpha) estimates in his instrument development work. The quality of life was divided in three levels: from 0-45 points (Low Quality of Life); 46-74 points (Medium Quality of Life); and 75-105 points (High Quality of Life).

Results

Caregivers characteristics. This study had *N* = 377 cancer caregivers, from which 31% were males and 69% females. They were part of six different age groups, starting from 18 years old until 66 or more. The greater percentage of the caregivers fell in the age – group 26-35 years (21.2%) and 36-45 year (20.2 %). The other groups had a similar distribution,:18-25 years (18.3%), 46 – 55 years (18%) and 56 – 65 % (17.8%).

The greater percentage of the caregivers had secondary education and high school (68.9%), a very small percentage didn't have any education (0.8%), or held postgraduate degrees (2.1%), while the caregivers with higher education were 24.9%. of the sample. Regarding their marital status 71.4% of participants were married, 22.3% single, 1.6% were divorced and 4.8% widowed.

Caregivers employment were in very low levels. Only 37.4% were employed, while 62.6% were unemployed. From the ones employed (n_p = 141), 39% were employed in the public sector, 38.3% were self - employed, while the others were in the private sector (22.7%).

Table 1 Family monthly income of caregivers, N=377

	Frequencies	Percentage	Value percentage	Cumulated percentage
>30000	182	48.3	48.3	48.3
30000 - 60000	142	37.7	37.7	85.9
60000-90000	24	6.4	6.4	92.3
90000-120000	10	2.7	2.7	95.0
120000-150000	6	1.6	1.6	96.6
150000 or more	13	3.4	3.4	100.0
Total	377	100.0	100.0	

Table 1 presents the family monthly income of the caregivers where it results that this is in very low levels. Only 11.4% of them had an income above 60000lek/per month, while a very large percentage of caregivers lived with minimal monthly family income. A family monthly income of under 30000lek had 48.3% of them, while from 30000 until 60000 lek were 37.7% of caregivers. One of the most frequent mentioned needs was the financial ones, which supports the findings regarding the income.

Regarding the quality of life for the average value is $m = 69.45$ $SD = 1.5189E1$. The median value was $M = 70$, while the minimum and maximum values were $min = 35$ and $max = 205$ respectively. Table 2 shows the quality of life under different categories. It is noted that only 21% ($n = 79$) of participants reported a high quality of life, the majority of them is on average (n = 199, 52.8%) and in the category of low quality of life are $n = 99$ (26.3%).

Table 2 Categories of QoL, N=377

	Frequencies	Percentage	Value percentage	Cumulative percentage
Low	99	26.3	26.3	26.3
Medium	199	52.8	52.8	79.0
High	79	21.0	21.0	100.0
Total	377	100.0	100.0	

The relation between employment and QoL. Participants employment and its relation to QoL is presented to the below tables (Table 3 and 4). Results were statistically significant for QoL ($p < .05$). QoL is influenced from the employment status ($z = -3.681$, $p < .001$), where the average values were respectively $M = 215.72$ for the employed participants and $M = 173.04$ for the unemployed ones.

Table 3
Employment and QoL

	Quality of life
Mann-Whitney U	12870.500
Wilcoxon W	40836.500
Z	-3.681
Asymp. Sig. (2-tailed)	.000

a. Grouping variable: employment

Table 4
Differences in QoL according to employment

	Are you employed?	N	Mean Rank	Sum of Ranks
Quality of life	Yes	141	215.72	30416.50
	No	236	173.04	40836.50
	Total	377		

The relation between family monthly income and QoL.

To explain the relation between criterion variables and monthly income in this study an ANOVA has been used and a post hoc Welch coefficient, which is suitable in the case of not fulfilling all the requirements for a parametric ANOVA. Family monthly income was recoded into three categories (from six initial). These were: "0 – 60000lek", "60000 – 120000lek" and "120000 or more". According to Table 5 QoL had statistically significant results in relation to the monthly income, where $F(2, 374) = 18.27$, $p < 0.01$,

Table 5
Relation between family monthly income and QoL

		Sum of Squares	df	Mean Square	F	Sig.
QoL	Between groups	7722.838	2	3861.419	18.274	.000
	Within groups	79030.775	374	211.312		
	Total	86753.613	376			

Table 6 shows the correlation between family monthly income and QoL. It can be noted that income has a moderate positive correlation with QoL ($r_s = .227$, $p<0.001$).

Table 6
Correlation between family monthly income and QoL

		Quality of Life
Family monthly income	Correlation coefficient	.227**
	Sig. (2-tailed)	.000
	N	377

**. Correlation is statistically significant at the 0.01 level (2- tailed).
*. Correlation is statistically significant at the 0.05 level (2- tailed).

Discussion

Perceived quality of life for cancer caregivers on this study had an average value of $m = 69.45$, $SD = 1.5189E1$. The median value was in M = 70, while the minimum and maximum values were respectively $min = 35$ and $max = 105$. The majority of the participants reported a medium QoL (52.8%). In the study of Nagel *et al.* (2009), which studied the whole popullation using the same instrument it was noticed that the average values were higher $m = 88.5$, $SD=9.5$. The author of the QoL Scale provides different results for the QoL for comparison (Flanagan, 1978). The average value for the QoL for a healthy popullation is m = 90, a score much higher that then one on this study ($m = 69.45$). Furthermore, in specific popullations, according to the author, there is a decline in the quality of life, albeit their average scores remain higher compared to the sample of this

study caregivers. Table 7 shows the different mean scores for these popullations. It is clear that these results compared to the caregivers of this study are relatively higher, which indicates for the problems faced by this study's sample.

Table 7

QoL average scores in different popullations

Vlerat mesatare të Cilësisë së Jetës në grupe të ndryshme

Studied group	Average score of QoL
Healthy group	90
Reumatismal diseases	83
Systemic lupus erithematosum	84
Osteoarthrit	87
Juvenile reumatoid arthrit	92
Post – traumatic stress disorder to israali patients	61
Fibromyalgia	70
Psoriasis, urine incontinence	82

While the majority of albanian workers have to balance work with family responsibilities, today's workplaces are still designed around the breadwinner-homemaker workforce of the 1950s. This outdated workplace model assumes that workers have someone at home to take care of family caregiving and domestic responsibilities. Changing workplace demographics have led to more working parents and more workers with family responsibilities.

Conclusion and recommendations

Caregiving has been identified as a chronic stressor around 30 years ago, where early findings reported the effects that the caregiving demands had in family members. The researches thereafter have advanced in order to explore the psychosocial aspects of caregiving, including their mental and physical health.

Caregiving for cancer patients can be very demanding because of the many responsibilities, particularly if the cancer is in an advanced stage (Longman, Atwood, Benedict, Sherman & Shang, 1992).

The recommendations regarding the discrimination of caregivers relates to the adoption of a model policy for preventing it, to providing workplace flexibility, to establishing effective and predictable scheduling of hourly jobs,k to developing and providing education and training to supervisors and managers and to offering support, resources and referral services when needed. These reccomendations could favor the employment of caregivers and therefore improve their socio – economic status and their quality of life.

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